
Promising Practices in Long Term Care Systems Reform: New Hampshire's Community-Based Service System For Persons with Developmental Disabilities

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New Hampshire's Community-Based Service System for Persons with Developmental Disabilities

As home and community-based support systems continue to grow and evolve, states are examining whether their current systems reflect fundamental participant and community values. A number of states are concluding that they need to put in place systemic reforms to ensure that their home and community-based support systems promote dignity, independence, individual responsibility, choice, and self-direction.

Systemic reforms are simultaneously addressing multiple aspects of community long term support systems in order to improve responsiveness to participants' needs and preferences. These initiatives are developing entirely new ways of designing, organizing, and managing community-based supports as a system rather than as a random collection of uncoordinated individual services. In some cases, this has required states to make fundamental changes to the administrative infrastructure of their home and community-based support programs.

Two design features in particular have repeatedly emerged as essential components of systemic reform initiatives:

- *Single Entry Points*, which provide persons with a clearly identifiable place to get information, advice and access to a wide variety of community supports; and
- *Person-Centered Services*, which place participants, not services or providers, as the central focus of funding and service planning.

The Centers for Medicare and Medicaid Services contracted with Medstat to examine approaches nine states took to developing Single Entry Points and Person-Centered Services to assist persons with disabilities to live productive and full lives in integrated community settings. We conducted on-site interviews with state officials, advocacy organizations and local program administrators and extensively reviewed written documents on policy proposals, administrative rules, and program evaluations. The emphasis of the resulting nine case study reports is on identifying transferable models that can be adapted for replication in other states and communities across the country, while acknowledging that some aspects of state systems may be unique to each state's culture, history and traditions.

Since most states have separate service systems for different populations, each case study will focus on a particular population. The focus of this report on New Hampshire is on service systems for people with developmental disabilities.

Overview of New Hampshire's Supportive Services System

Innovative Aspects

The New Hampshire Supportive Services System for people with developmental disabilities is substantially funded through a Medicaid waiver program (referred to HCBC-DD waiver). It is distinguished by a number of innovative features, including a single point of entry into the

system through 12 Area Agencies, a strong community living program, considerable regional control with significant stakeholder input, and finally, innovative program management (including individualized budgets). Within the waiver, New Hampshire has a self-directed services program that allows participants and their families control over funds budgeted to them.

Twelve regional Area Agencies are responsible for almost all aspects of the community-based service system including enrollment, program management and coordination of service delivery. Participants choose from an array of services that are either provided directly through the Area Agency or through its subcontractors, and there is a real and growing emphasis on independence and self-determination.

Another innovative aspect of the New Hampshire program is that the Area Agencies are the locus of information, support and services for all people with developmental disabilities and their families, whether or not they are Medicaid eligible. Area Agencies coordinate Medicaid's waiver program and other services for people with brain injuries, as well as Medicaid supports for young children with developmental disabilities and their families.¹ In other words, the supports are truly integrated and the same single entry point system and integrated services array works for the child with developmentally disabilities who lives with his or her family and works still for the Medicaid eligible adult who moves out on their own into the community.

Spending and Participants

A brief overview of the community based system for adults with developmental disabilities in New Hampshire is necessary to lay the basis for later discussion because the integration of services and programs in the State make the distinctions in service funding sources difficult to see without expressly laying it out. In 2002, 2869 people with developmental disabilities and their families had services funded through the Medicaid HCBC-DD waiver; of those, 1,488 individuals received personal care/residential services. Sixty-five percent of those who receive personal care/residential services live in small community residences which provide services to one or two individuals; these are referred to as Enhanced Family Care Family Homes. Only 18 percent of residential services in NH are provided in staffed residences which typically provide services to four or fewer individuals as New Hampshire has phased

¹ New Hampshire has two other waiver programs and a state plan service that are important to know about. The first is a longstanding program for persons with acquired brain disorder. This ABD waiver serves about 90 participants and has a waitlist of 25. The ABD waiver serves people who were formerly institutionalized and those who have been diverted from institutions. There is also a waiver program for the elderly and those with chronic illness (the HCBC-ECI waiver) that serves 1800 people and has no waitlist. The ECI waiver, which is administered through NH's Division of Elderly and Adult Services (DEAS), offers a more limited service array than is available through the other waiver programs. This waiver is undergoing change to re-direct the program toward greater self-direction in personal care services. Finally, although not a waiver program, the Medicaid state plan offers personal care attendant services specifically for people who use wheelchairs and are capable of self-direction. The service has about 150 participants and is fully self-directed. All of these programs come into play as New Hampshire continues on the path toward self-directed services for all people with disabilities and seeks to create a more unified approach to services across the lifespan and across different disabilities requiring long term supports.

out almost all large group homes. About 200 individuals, or eighteen percent, live in their family homes with blood relatives. As an innovator, New Hampshire ranked fourth in the nation for community residential placements in settings with six or fewer residents in 2000.

New Hampshire spent \$118.5 million on HCBC-DD waiver services in 2002. The average per capita waiver expenditure in 2002 totaled about \$41,300. Analysis of 2001 data show that, in New Hampshire, 99 percent of all spending on developmental disability services is spent on community-based services relative to a national average of 75 percent.

About 3,000 people with developmental disabilities and their families received Area Agency supports through State-only funds, under a service program referred to as Family Supports, which totaled about \$4.2 million in 2002.

New Hampshire also has a relatively new in-home support “Independence Plus” waiver for children with developmental disabilities, which began in Spring 2003 and is modeled on the self-directed service option in the adult waiver and the “cash and counseling” demonstrations of other states. New Hampshire was the first state to initiate this type of waiver that allows participants choice and control over support services. The program, known in the state as In-Home Support (IHS waiver), is projected to serve about 200 children and provides personal care, consultation, respite, environmental and vehicle modifications, and service coordination. Like the HCBC-DD program for adults, this program for children with developmental disabilities and their families is coordinated by the Area Agencies.

Home and Community-Based Supports

The creation of the supportive services system to provide services to persons with developmental disabilities began in 1981, when the State began to bring people out of its only state ICF/MR institution.

Persons with developmental disabilities receive all support services through 12 Area Agencies. The primary waiver services are:

- SERVICE COORDINATION/CASE MANAGEMENT to assist in gaining access to waiver and non-waiver services, and to provide ongoing monitoring of supports provided;
- DAY HABILITATION SERVICES to assist the participant in acquiring, refining and improving self help, socialization, and adaptive skills necessary to successfully reside in home and community based settings. The service is provided in non-residential settings.
- SUPPORTED EMPLOYMENT Services to provide paid employment, as well as skills and training necessary to sustain paid work;
- PERSONAL CARE SERVICES offering assistance and training to individuals to maintain and improve their skills in basic activities of daily living.
- COMMUNITY SUPPORT SERVICES to provide assistance in instrumental activities of daily living: shopping, money management, food preparation, laundry, household maintenance, and social skills for individuals who are living independently in the

community or are preparing to do so. These services can begin while the participant is still living with his or her family;

- ENVIRONMENTAL ACCESSIBILITY ADAPTATIONS for home and vehicle which are needed to ensure the participant's health, welfare and safety or which enable the participant to function with greatest independence;
- RESPITE SERVICES to provide short-term coverage due to the absence of the regular provider or caregiver. Available in all home and community residential settings.
- CRISIS RESPONSE SERVICES to provide consultation, clinical evaluation, and short term staffing supports to individuals in behavioral, emotional, or medical crisis which are available around the clock every day;
- ASSISTIVE TECHNOLOGY SERVICES to provide help for participants in selecting, acquiring and using assistive devices;
- SPECIALTY SERVICES to provide assessments, consultations, training and supervision of staff, as well as evaluations of outcomes for persons whose needs in medical, behavioral, therapeutic, health or personal well-being require services which are highly specialized; and
- CONSOLIDATED DEVELOPMENTAL SERVICES to provide assistance and resources in order to improve participant and family opportunities and experience in living, working, socializing, recreating, as well as personal growth, safety, and health. Participants and families have freedom to select and control their supportive service providers.

The State rules make clear that anyone who has a condition that meets the definition of developmental disability is eligible to access services through the Area Agency, however the amount, duration, and scope of services provided through the State-only funding stream for Family Support are more limited than Medicaid waiver services. Family Supports are those services that enable the family to continue to care for the participant. Examples of these services include information and referral, respite, and assistive technology services, as well as other services that enable families to support people with developmental disabilities at home.

Program Management

The New Hampshire Department of Health and Human Services (DHHS) administers the Medicaid program and programs in developmental disabilities, mental health and substance abuse, disability/chronic illness, and the child welfare program. The Division of Developmental Services (DDS) within DHHS administers the HCBC-DD waiver program and has direct oversight responsibility for service quality and performance monitoring. The Division also has responsibility for overall developmental disability policy.

While the State has funding and oversight responsibilities, the HCBC-DD funded services are locally administered through 12 contracting Area Agencies, allowing for substantial local control over the program that leads to variation and evolution in programs across locations according to the needs of those served. The Area Agencies differ in whether they provide services or subcontract for them – some Area Agencies subcontract for most services, while a few agencies provide most of the services themselves. Most Area Agencies use a combination of these two approaches. Among the 12 Area Agencies, there are about 70

agency subcontractors, and as will be discussed later, there are many, many individual providers selected by participants who are not staff of the Area Agency or subcontracting agency staff.

The State Division of Developmental Services links to the Area Agencies through State-level division liaisons, who do the fiscal and quality oversight and reporting. All Area Agencies are responsible for:

- Regional Planning
- Eligibility assessment (for non-waiver services)
- Family support
- Service provision
- Service coordination
- Investigation/Resolution of non-abuse complaints and grievances
- Management of regional waiting lists

Waiting Lists

Waitlist issues have been prominent in New Hampshire and have in fact brought about several lawsuits. In 2001, the legislature stipulated that the DHHS must develop a plan to reduce the waitlist, develop a minimum amount of services participants would receive, and establish service levels among other requirements. DHHS did develop such a plan and identified associated costs. The legislature has not funded the comprehensive plan but has continued to make ad hoc supplemental appropriations specific to the purpose of moving people off the waitlist. As of June 2003, there were 417 people on the waitlist, and through an appropriation of \$3.3 million almost 200 people from the waitlist will enroll in the waiver during the Fall of 2003.

The NH DD Waitlist has three categories of prioritization. The top priority includes those people who have current needs and who are at imminent risk of physical or emotional harm or significant regression. The second tier list includes those who will have unmet needs in one to two years and who will be at imminent risk of physical or emotional harm or significant regression. (This category generally refers to people whose support arrangements will be changing in a couple years such as children aging out of the special education system, older adults with aging caregiver parents, for example.) The third level priority list includes those people with current or future needs but who will not be at imminent risk.

Evolution of New Hampshire's Supportive Services System

Impetus for Reform

New Hampshire's self-direction movement began about 20 years ago with the decision to downsize the State's institution for persons with developmental disabilities, the Laconia State School (originally founded as the School for Feeble-Minded Children in 1901). The decision to scale back the institution was made after an extensive court battle led by the families of Laconia residents and the US Department of Justice. A court order in the Fall of 1980—that

every Laconia resident be in the least restrictive setting possible—was precipitous to the decision. Between 1981 and 1991, when the facility was officially closed, New Hampshire transitioned to a system of community services and supports for people with developmental disabilities. Although a major change in service format for people with developmental disabilities occurred with the end of institutional care, the New Hampshire system continues to evolve with a focus today on strengthening the role of participants in controlling and directing their support services.

As an alternative to the institution, private, nonprofit entities—Area Agencies—were created to serve all persons with developmental disabilities in their region while under contract with the State. An important point to stress here again is that the Area Agencies are the focal point for services for all persons with developmental disabilities (both adults and children) and their families, regardless of whether they may be eligible for Medicaid.

The Area Agency community model started with three pilot sites in the early 1980s, and was subsequently expanded. The model was applied often by building on local arrangements that were already in place including organized parent groups. To add impetus to the approach, State-level advocates also were very interested in establishing local control for these agencies, which was seen as an extension of individual control.

At first, the State had minimal funding for these agencies and most of the supportive services were expected to be community funded. In fiscal year 1984, the State started using the HCBC DD waiver for community services and within the year Medicaid was funding about 86 percent of services through a waiver, which is now in its 20th year of operation.

In the mid-1990s, the State further recognized the value of waiver funding and decided to convert almost of its small private ICFs/MR to residential group homes under the waiver. That process was completed by the year 1996. (There is one private ICF/MR remaining in the State, which serves a small number of children, under the age of 16, who have serious medical needs.) More recently, there has been a strong emphasis on developing small community residences for participants, rather than large group homes. New Hampshire policy reflects the belief that larger group homes have a tendency to limit choice and independence and therefore, have been all but phased out.

An impetus to the most recent set of reforms in the developmental disability service system was a demonstration project sponsored by the Robert Wood Johnson Foundation at one site in the State to test the feasibility of self-directed supports. The demonstration concluded in 1999. At the time of demonstration, there was a growing recognition in the participant and advocacy communities that, although people with disabilities had been ‘liberated’ from institutions, they were increasingly constrained by a system that relied on professionals: professional determinations of ‘client’ needs; professional determinations of what ‘clients’ should try to achieve; and professional determinations of the services that would address both those areas.

The initial demonstration showed positive results early on, which energized the community. Thus began the most recent aspect of reform: self-directed supports.

The State has crafted rules and policy to further the development of a community support program. Importantly, the law and ensuing regulations establish the requirements, role and responsibilities of Area Agencies, the covered services, and the process by which an individual's service array will be determined. State regulations governing eligibility and services were revised early in 1999 to reflect the key value of self-determination. These regulations lay the basis for the self-directed focus of the program in New Hampshire today:

“All services shall be designed to promote the individual's personal development and quality of life in a manner that is determined by the individual...Services shall: Meet individual needs in personal care, employment, adult education and leisure activities; Ensure, to the extent possible, that the individual is free from abuse, neglect and exploitation; Increase the individual's experience of community in a variety of integrated activities and settings; Provide opportunities for the individual to exercise personal choice, independence and autonomy within the bounds of reasonable risks; Enhance the individual's ability to perform personally meaningful and/or functional activities; Assist the individual to acquire and maintain life skills, such as, but not limited to, managing a personal budget, participating in meal preparation, or traveling safely in the community; and; Be provided in such a way that the individual is seen as a valued, contributing member of his or her community.”

“The environment or setting in which an individual receives services shall promote the person's freedom of movement, ability to make informed decisions, self-determination, and participation in the community.”

“An individual or guardian may select any person, any agency, or another Area Agency as a provider to deliver one or more of the services identified in the individual's service agreement. All providers shall comply with the rules pertaining to the service(s) offered and meet the provisions specified within the individual's service agreement...”

Stakeholder Roles in Reform

Stakeholders have been crucial in the development, implementation, and operation of the New Hampshire HCBC-DD waiver program. Stakeholder involvement has always been the cornerstone of the system, from the first lawsuit that led to the closure of the State institution and forced the question of appropriate alternatives. A State official noted that the waiver program is a community stakeholder program because of the structure in place to respond to the needs of individuals and families.

In the mid-1980s, the State put rules into effect mandating board member requirements for the Area Agencies; the rules effectively codified participant involvement. For example, Area Agency boards must be comprised of one-third consumers, one-third local community members, and one-third professionals.

In addition to community control of the Area Agencies through membership on the Board of each Agency, program participants and their families have numerous other avenues by which

to participate in the development of policy, as well as the implementation and operation of programs. In fact, avenues of participant and family input have recently expanded as a result of new initiatives in the State to build on the participant-direction developed in the adult developmental disabilities arena by applying it to other populations such as elders, and children with chronic illness and developmental disabilities.

In terms of participant and family input in the developmental disability arena, first and foremost, there are Family Support Councils. These Family Support Councils, created in 1989 and specified in State law, are organized in each of the 12 regions of the State. The Councils receive State funding each year. Last year the amount was just over \$1 million. Each of the 12 Councils elects a representative to the State Family Support Council, which meets every other month with the Division of Developmental Services to advise the Division as well as to share information among themselves. There is a statewide annual Family Support Conference.

In addition to advising and working with State officials, local Councils are an advisory body to the local Area Agency on family support issues and planning. In consultation with the Area Agency, each local Council can direct the spending on State-only funded Family Support services by determining what services will be made available in their respective region.

As mentioned earlier, these flexible Family Support state funds are used specifically to strengthen family supports and fund services for families not served by the HCBC-DD waiver and to supplement services for waiver-eligible families. Family support services directed by the Family Support Councils are defined as whatever is needed to support the continued ability of families to care for their family member at home. Respite is often a covered service. More frequently, State-only funded family supports include information and referral to community resources. Each Family Council also has a legislative advocacy representative who keeps the Council and community apprised of developmental issues in the legislature.

In addition to Family Support Councils, there is another important stakeholder group, People First. Created in the early 1990s, the organization of self-advocates receives funding from the Division of Developmental Services and has 14 chapters statewide. The State-level People First acts as an advisor to the State Division of Developmental Disabilities and its Board meets with the Division's management team quarterly. The DDS has an assigned division liaison to People First to facilitate ongoing communication and to solicit input on particular issues as they arise.

In addition to these two key stakeholder groups, there are a variety of other organizations that advocate or advise on policy matters. For example, the Developmental Disabilities Council is federally mandated and funded to support research and advocacy around developmental disabilities. Sixty percent of these Council members must be people with developmental disabilities or their family members. The Council also works to develop community leadership on developmental disabilities. The Council has a strong relationship with the State Department of Health and Human Services.

There is also the recently established Leadership Policy Council that advises the Office of Commissioner of the State Health and Human Services Department on issues related to

developing community based services that serve across the lifespan and different disabilities, with a specific focus on self-directed services. The Leadership Policy Council is composed of consumers and policy experts in equal proportions.

There is a new Joint Quality Committee made up of people with disabilities, elders, and their families to examine current approaches to assessing quality and devising new methods that support the improvement of services and participant choice.

There are also other advocacy groups that operate at the State and local levels. One of these, the University of New Hampshire Institute on Disability runs a yearly leadership training program for families which is funded by the Division of Developmental Services and the Area Agencies.

Single Entry Points: Facilitating Access to Needed Supports

Area Agencies

The 12 Area Agencies act as a single entry point in their locality for home and community based services for persons with developmental disabilities. While this discussion is specific to adult DD services, it is important to remember that Area Agencies also manage services for the Acquired Brain Disorder (HCBC-ABD) waiver and the new in-home services (or Independence Plus waiver) for children with developmental disabilities (HCBC-IHS waiver).

With regard to adult DD waiver services, the Area Agencies provide all of the information and assistance necessary for participants to receive services and access needed supports. They also assist in gathering the information needed for the State to make a determination of eligibility for Medicaid and waiver services.

People learn about the Area Agencies and about waiver policies in general through newsletters, brochures, and referrals. While there is a single entry point into the system of services for adults with developmental disabilities, there are numerous referral sources such as local government, housing agencies, mental health providers, schools, and health care providers among others. Outreach about services for people with developmental disabilities is fairly extensive, so referrals into the system come from a variety of places. While Area Agencies are the gateway to a host of important services, they are the source of crisis intervention services. They have staff on-call to respond to crises around the clock, including weekends.

Eligibility Determination

The eligibility process for Medicaid waiver services is two-fold. People apply for Medicaid coverage at State DHHS district offices. Once approved, they will be assessed for waiver program eligibility. This process requires the Area Agency to gather relevant information about the potential participant's condition – past clinical assessments and diagnosis-related information. This information is captured on a standardized form used by all Area Agencies.

At the same time, the Area Agency works with the applicant to develop an Individualized Service Plan and service budget (which are discussed in detail below). All this information is sent to the State DHHS for review and approval. There is a State-level appeals process for both the Medicaid eligibility determination and the waiver program determination.

Non-financial eligibility for waiver services is based on diagnosis: mental retardation or closely related condition, epilepsy, autism or a specific learning disability, or cerebral palsy, with onset prior to age 22. The applicant must have a severe functional deficit that impairs daily independent functioning, is expected to be life-long and requires an ICF/MR level of care.

Integrated and Person-Centered Supports

This series of case studies on state long term supports initiatives focuses on two primary components of systemic reforms. The first, as described in the previous section of this report, is a single entry point designed to provide an identifiable place where people can get information and advice, and can access a wide range of community supports. The other essential component is a system of integrated services that places participants, not supports or providers, at the center of funding and support planning.

Integrated services systems, as discussed in the following sections of this report, have three key features. First, by integrating a wide range of support options, they enable persons to make meaningful choices about their living arrangements, the types of supports they receive, and the manner in which services are provided. Second, by integrating systems management across different funding streams, the State's ability to achieve intended participant and program outcomes is enhanced. Third, by integrating program supports with generic community resources, participants have better access to employment, transportation, and other assistance in making the transition to independent living and building natural relationships. New Hampshire has been a leader in developing a person-centered and integrated approach to support services.

In New Hampshire, integration means something more than access to an array of services. Integration of supports with the community in New Hampshire also means that the funding sources are relatively seamless, and people who are not eligible for Medicaid receive services through the same structural mechanisms as those who receive Medicaid coverage. The service system is seamless in another way as well: it is the same service system and mechanisms that serve people with developmental and cognitive impairments throughout the life span. Area agencies are the locus of service for families of young children through the In-Home Supports waiver, families of those with severe brain injuries, as well as the locus of support and information for adolescents and adults with developmental disabilities.

Person-Centered Planning

Participants and their families have a choice of providers, and Area Agencies have a mandate to facilitate individual planning. The intake and planning process has changed in New Hampshire over the years. In some ways, periodic State fiscal constraints have altered the

service delivery system—and the planning system. Originally, the intake person would construct an individual service plan (ISP) based on goals and objectives for an individual, as determined with the professional expertise of the case manager.

Today, the ISP is called a Service Agreement, which reflects a change in focus and purpose for the document. Service planning today is focused on what the participant wants to accomplish and what the staff agree to do in support of the participant's goals. Agency commitments specified in the service agreement might include deliverables such as installing a ramp, arranging for swimming lessons, or lining up job interviews. The service agreement is no longer viewed as an opportunity for a clinical review focused on individual improvement through goals and objectives as determined by a professional, but rather it is an opportunity for the family and participants to express their service needs and life goals. The service agreement includes more than the specific services that will be provided by others, but goes further to include goals and objectives of the participant.

There has been extensive and on-going training around person-centered planning for everyone in the system. There is a statewide core curriculum, available on CD-ROM, for which local colleges will provide credit upon course completion. This is a joint effort between the State and the Area Agencies.

Individualized Budgets

An important component of service coordination in New Hampshire is the individualized budget process. Every person in the HCBC-DD waiver program has a line item budget amount related to their service mix. Area Agency funding requests are now made at the person-level and this information is forwarded to the State for review and approval at the same time as condition-specific information is sent for waiver eligibility determination. Originally, when the community program established group homes, budgets were facility-based, essentially covering the expenses of the home and participant services based on the number of beds in a home. Over time, budgets have been refined to reflect each person's individual needs and have become portable: the funding follows the person rather than having the funding tied to each service setting.

The individualized budget is comprehensive and not specific to just those items and services covered by Medicaid. The budget accounts for all expenses, such as wages for support staff (paid by Medicaid) and rent (paid by the participant from their cash benefits such as SSI). The individual budget therefore, accounts for waiver and non-waiver supports and expenses while at the same time it includes non-Medicaid revenues to cover non-waiver services. In this manner, the individualized budget reflects the total needs and desires of a participant, and the service agreement can be comprehensive, accounting for all aspects of a person's life.

The State prior-authorizes the individual budget and all waiver services. Individualized budgets are developed by the Area Agencies, while spending against the individualized budget is tracked by providers, the Agencies, and the State liaison staff.

Array of Available Community Supports and Freedom of Choice

The Area Agencies help families with identification of community supports, their choice of providers, and services. Waiver-funded supportive services coordinated through the Area Agencies include: personal care, community supports, family supports, crisis intervention, assistive technology, specialty services, and consolidated developmental services.

Participants work with a service coordinator to select their services and service providers. Participants may have friends and relatives become their providers, however, a spouse or a parent of a minor cannot be a provider. It is important to note that participants can select a service coordinator who is not on Area Agency staff. Regardless of whether the service coordinator and providers are Agency personnel, the Agency has the responsibility to ensure participant safety. For example, it is the Area Agency's responsibility to conduct background checks on individuals requested as providers, if those individuals are not already approved. One Area Agency had about 300 participants receiving services through 700 small service contracts, in addition to the 14 large subcontractors.

Freedom of choice is an inherent focus of this waiver program and is codified in the State program regulations. Participants and their families can select anyone to be their provider of services if the individual meets system's standards and qualifications. Area Agency staff are required to explain the options and participant rights at the beginning of the service planning process. Participant or family signature attesting that they were informed of their choices and rights is part of the Service Agreement process.

Self-Directed Supports/Consolidated Developmental Services

New Hampshire was among the first States in the country to modify the HCBC-DD waiver to allow participants and their families to assume control of their own budget and serve as their own service coordinator, selecting needed services and providers. In waiver parlance, this program is called consolidated developmental services. Like other aspects of the waiver, families and participants can choose a service coordinator outside the Area Agency. However, in the self-directed program, they develop their own service plan, hire their own workers, and complete other necessary tasks such as submitting monthly attendance reports and evaluations of service performance. This model is scalable based on the individual's and family's desire and ability to control and direct services.

As noted earlier, providers cannot be a participant's spouse or parent if the participant is a minor. The Area Agency can act as the fiscal intermediary for self-directed participants and families by handling payroll and payments; however the family may choose an outside fiscal intermediary as well. In addition to providing payroll services, oversight responsibility for the program still rests with the Agency. While all Area Agencies provide this consolidated developmental services option, one of the Area Agencies has a separate self-directed services department to work specifically with people who chose the consolidated services option.

The State DHHS reported that in 2002, 29 participants availed themselves of this service approach, for a cost of about \$895,000. The average per capita costs of approximately

\$31,000 for consolidated services remain well below the average per capita waiver costs of \$41,300 for 2002. In part, State officials felt that those who choose the self-directed option and participate in the budget process tend to be more conservative in their use of resources due in part to increased comprehension of actual service costs.

Participation in the self-directed service option remains low after several years of operation. State officials believe this is due to a number of factors. First, the option is not always widely promoted by Area Agency staff because, while some Agencies have embraced the concept, other Agencies remain somewhat reticent about the operational changes required and their implications. Second, the option requires considerable work on the part of participants and their families; some families have a certain degree of burnout by the time they are eligible to obtain waiver services and are therefore not in a place where they can adequately take on the responsibilities associated with self-direction. Third, waiver participants include people who originally received services at Laconia and self-direction is a concept they are not used to and have not embraced.

However, State officials believe that participation rates will grow in the future, particularly as a result of the in-home support waiver for children which is completely oriented to self-direction. The new generation of families will have become used to the basic concepts and operational components by the time their children age into the adult DD waiver.

Coordination with Health Care Services

The linkage between the developmental disability system and health care is not the strongest component of developmental disability policy in the State. A significant exception to this is a training program that allows non-medical personnel to administer drugs to waiver participants.

With regard to administration of pharmaceuticals, New Hampshire allows trained, tested and approved non-medical personnel to administer drugs to waiver participants residing in the community. This was accomplished through an exception to the State Nurse Practice Act. With the exception of injectibles, all types of medications in all forms may be administered. This significantly reduces program costs, helps ensure that participants are able to get their medications as needed, and is consistent with the tenets of independent living and self-direction. State trained and designated nurse trainers train non-medical providers in the community to perform this service, and the Area Agencies track performance through individualized medication logs.

Service providers can only be approved to administer medications after an eight hour training conducted by an approved nurse trainer, scoring 80 percent or higher on a written exam, and demonstrating knowledge about the medications to be administered to the particular participant, (including side effects and special monitoring that might be required with administration). The certification is valid for a year.

The authorized provider must maintain a medication log meeting certain standards, which is reviewed by a registered nurse with a periodicity that varies by size of residence from

monthly to semi-annually. Medication log data and authorized provider information is used by each Agency to produce two semi-annual reports of medication administration. These reports record every dose of each medication administered, any adverse occurrences and the immediate corrective action taken for each incident, identification of any incident trends and specification of related corrective actions plans. One report is focused on community settings; the second is focused on providers or provider agencies. The Agency reports are submitted to a State-level Medication Committee for review; this Committee can accept the report, request more information, or identify areas of non-compliance and recommend corrective action. If results are unsatisfactory, the provider and /or nurse trainer can be de-certified.

Integration of Systems Management

Coordination within and among the Area Agencies

The Area Agencies have worked together to coordinate certain functions. The Agencies and the State worked together to develop a common intake form, and standardize parts of the assessment such as the IQ test and functional assessment.

There is a collaborative partnership of Area Agencies, the Community Support Network, Inc. (CSNI). It is a non-profit organization established to facilitate the sharing of best practices, conduct joint purchases, purchase health insurance, and collaborate on a variety of efficiency and quality initiatives. The CSNI has played a major role in facilitating the development of standardized survey instruments and development of a new report on system quality, the *New Hampshire Quality Outcomes Partnership Report*, which is discussed in greater detail below.

Various Area Agency staff get together regularly on an inter-Agency basis with State staff under the auspices of the State Agency to identify common problems, share best practices, and coordinate approaches to issues:

- NH DD Nurses meet monthly
- Business Managers meet monthly with the DDS finance manager
- Service Coordinators meet monthly
- Complaint Investigators/Rights Protection liaisons meet monthly
- Executive Directors meet monthly with the DDS Director
- Family Support Coordinators meet monthly
- Quality Assurance Directors meet every other month with DDS management and Division liaisons
- Respite Coordinators meet every six weeks specifically with State staff from the Child and Family Unit of DDS.

There is also an effort to coordinate across programs within each Agency and across subcontractors. Area Agencies have monthly meetings with the directors of all subcontracting agencies in order to closely manage these contracts. As mentioned earlier, one example is the Area Agency which had about 300 participants receiving services through 700 small service

contracts, in addition to the 14 large subcontractors. Coordination and monitoring are especially important with the number of providers involved.

Integrated Information Systems

New Hampshire is in the process of updating its management information systems to better coordinate information for the Area Agencies, subcontractors, and waiver participants. A strategic planning process within the State determined that, while the necessary data pieces for coordination and full information existed, the information needed to be combined into a single database, preferably a web-enabled system.

The newly integrated information system is being built in modules, so that each module is tested and user feedback incorporated into subsequent modules. The system will be accessible by Area Agencies and their service coordinators from anywhere through the Internet. The system can only be accessed by certain approved individuals.

The first effort in the move toward an integrated information system was the budget system module, with individual expense budgets by person and service. This was followed by a web-based prior authorization application (for services that are pending, approved, etc.) that is crucial for service coordinators. The next module covered was a rules and regulations database and then the reporting module (for services, budgets and indicators). The next two MIS modules are the intake module and the billing system.

Quality Assurance Strategies

New Hampshire uses a mix of traditional quality assurance strategies and, importantly, newer quality strategies that speak to the heart of the system's goals: participant satisfaction with services and the extent to which services support community living and independence. What follows is a brief look at some of the more traditional quality assurance strategies employed by the State, as well as some of the innovative strategies that keep the system focused on the goals of self-direction and independent living.

Traditional Strategies

In addition to those aspects of quality assurance already mentioned in the report, such as stakeholder participation, inter-Agency information sharing, and medication administration oversight, New Hampshire relies on many of the traditional quality assurance mechanisms.

Provider Licensure and Certification, and Area Agency Redesignation—At the State level, licensure and/or certification (and related renewals) of support providers, including Area Agencies, is a key feature of quality assurance. Much of the licensure, certification and redesignation involves compliance with standard requirements, such as health and safety standards, staffing requirements (including training), quality improvement systems, and financial requirements and audits for providers and Area Agencies. Providers are subject to on-site reviews by Area Agencies with State look behind site visits. Area Agencies are subject to site visits by State staff. Also, the State links to Area Agencies through its own staff –

designated division liaisons – who are assigned to each Agency and who are responsible for ongoing fiscal and quality oversight. The particular aspects of Area Agency recertification that innovate in assessing the quality of self-direction and support activities are discussed, separately, below.

Neglect, Abuse and Human Rights—There are assurance mechanisms to address neglect, abuse or other rights violations at both the State and Area Agency levels. All neglect, abuse or human rights violations are reported to, and investigated by, the State while other complaints are first investigated at the Area Agency level. The State trains Area Agency level investigators (who are often independent contractors rather than employees of the Area Agency) who do quality and other review on all reported cases. State investigators can participate with Agency investigators and oversee the investigation process. Mediation and an optional informal complaint resolution process are available to participants and families at the Area Agency level; however, this is only an option for complaints other than abuse, neglect or other rights violations.

Mortality Reviews—There is also a mortality review process in place since 1999 that requires an Area Agency to report any participant death to the State within 24 hours, which allows time for the Commissioner of Health and Human Services to ask for an autopsy, if indicated.

The mortality reviews are used by State and Area Agency staff to examine trends over time and to improve ongoing service and program quality. The reports are also used to identify indicators that signal a potential vulnerability of people with developmental disabilities to particular illnesses and accidents that would require particular program attention.

Quality Assurance in Self-Direction

What is most interesting about the New Hampshire approach is the movement toward quality assurance centered on participants' experiences relative to their own expectations and goals.

Individual Checks on Participant Satisfaction—Part of this assurance requires the service coordinators to visit participants to ascertain whether delivered services met participant expectation, in addition to a more standard role of checking to see if services were delivered. More recently, under the consolidated developmental services option (self-directed supports) participants are expected to evaluate and report on their satisfaction with services relative to both their needs and expectations.²

Evaluating Agency Roles in Self-Direction (Redesignation) — Another avenue of evaluation of self-direction pertains to the Area Agency Redesignation process – the Area Agency must demonstrate the extent to which it promotes participant choice, control and satisfaction. This is a particularly innovative part of the overall redesignation process, the more traditional aspects of which were discussed in the previous section.

² In the new In-Home Services waiver for children, (HCBC-IHS) the quality assurance mechanisms are similar to those in the HCBC-DD waiver. One new component in the children's waiver is a family stress measurement. Reduction in family stress is a measure of whether the waiver is achieving its objectives.

The redesignation process includes forums for participants and their families to report their experiences and opinions; interviews with: collaborating agencies, Family Support Council members, management team, Board of Directors, and support coordination staff. All direct care service providers are surveyed as well as invited to one of several forums to provide feedback on agency performance. The State advertises in the local newspaper to specifically solicit community input.

Adult Outcomes Survey—One of New Hampshire’s major quality initiatives that again demonstrates the State’s commitment to self-direction is the Adult Outcomes Survey. New Hampshire interviews 10 percent of waiver participants (and at least one other person with a relationship to the participant). This Survey is a major component of the QA process.

In terms of the Survey mechanics, participants in each region are selected at random from all waiver participants. Interviews are conducted by the State Division Liaisons and an Area Agency staff person, and these individuals reconcile the answers between the waiver participant and the family member interviewed, although the answer from the participant is always taken as the primary opinion. The State Division Liaisons writes an individualized report that goes to the individual/family/guardian as well as the Area Agency for any necessary follow up. A comprehensive regional report is also written which compares Area trends over years, and the report goes to the Area Agency, its Board of Directors and the local Family Support Council to assist in yearly strategic planning. The State combines all of the local Adult Outcomes Surveys to produce a statewide report that is broadly distributed and forwarded to CMS along with the annual 372 reports.

The Survey has questions in nine domains: home environment, paid work, volunteer activities, community participation, transportation, finances, health, assistive technology, service coordination, rights, and planning process. Questions within each domain query about participants’ desires, ability to make choices relative to those desires, and level of social involvement in the community. It is a qualitative approach that can produce quantitative results.

Employment Report—Each Area Agency produces an Employment Report that is submitted twice annually to the State Agency. The Report has been required since 1996. Each Agency must report on the number of participants employed, the type of work, the average hourly wage, the average number of weekly hours worked, as well as the age and disability level of those employed. The State uses this information to compare regional performance and identify those local Agencies that need to improve performance. This State report is shared with all local Agencies.

Family and Provider Surveys—The Family Survey reaches about 1,000 families that have a member with developmental disabilities living at home. This is a standardized survey fielded by each Area Agency. The survey was implemented three years ago; prior to that time, family satisfaction surveys were fielded by some Area Agencies using different instruments. Those efforts have been replaced by this standardized statewide effort.

Service providers are also surveyed annually by each Area Agency. This effort began at about the same time as the Family Survey. A uniform instrument is used statewide. The effort, like the Family Survey, is coordinated by the Agency collaborative (the Community Support Network) and the State Division of Developmental Services.

Quality Outcomes Partnership—The Quality Outcomes Partnership began in 1996. It is collaboration between the State Division of Developmental Services and the Community Support Network (which is the collaborative of all local agencies). The Partnership developed a set of common outcomes indicators by which to measure quality of the system and its services.

The Partnership used existing data sources such as the Adult Outcomes Survey, Agency financial reports, employment reports, and the provider and family surveys. These sources together produce a comprehensive, statewide assessment of the developmental disabilities system overall. This assessment is contained in the annual report, *New Hampshire Quality Outcomes Partnership Report*. Three annual reports have been produced. Collectively, these reports provide a longitudinal look at trends in the system and help to identify system strengths and weaknesses over time.

Emphasis on Community Living

Over 90 percent of New Hampshire support services are delivered to persons in a home setting. This is possible because New Hampshire emphasizes community living, and there are a number of innovative housing arrangements used by participants in the waiver program. More than 95% of homes have three or fewer residents, although most of the residences have two or fewer participants. As mentioned earlier, homes with one or two participants living with an unrelated caregiver are referred to as “enhanced family care.” State regulations allow homes with three or fewer people to receive certification but do not require them to be licensed. Certifications for small residences focus on the program, the Service Agreement, and whether the service agreement is being followed. For group homes with four or more people, a license is required in addition to certification.

Another important issue for New Hampshire is strengthening relationships among the program, its participants and a broader cross-section of the community, such as business and religious leaders. The State has a federal grant to plan development of a model community. The process requires involvement of the whole community in making the town fully accessible to all people with disabilities. Despite all the progress and innovation in New Hampshire, there remains a need for a better understanding of people with disabilities in the broader community beyond those who have a relationship with someone with a developmental disability.

Lessons Learned

New Hampshire has moved through several stages in the evolution of its support system for those with developmental disabilities and it has learned a great deal along the way. It went from having a large state institution as the focus of the system, to use of smaller ICFs/MR, to group homes, to a sustained and successful effort to move people into small and intimate

family/community homes. The people of New Hampshire have learned that it is the small living environment where choice, independence and relationships can best be fostered and supported.

Another lesson from New Hampshire is the degree of support for change and improvement that can come from involved stakeholders. Stakeholder momentum has been behind every significant change in the New Hampshire system. It has been suggested that the high degree of stakeholder input into design, as well as stakeholder roles in ongoing operations and policy, has led to the high degree of support for the State's system overall. State officials also felt that forward movement on self-direction would not have been possible without the support and flexible approach of the Region I Office of the Centers for Medicare and Medicaid Services.

While New Hampshire has an innovative program with more emphasis on community services than most states, some advocates are hoping the State will become even more creative in its programming. Although it has taken time to become fully oriented to participant-directed services and to have it work well, the implementation effort may prove to be worth the time and energy. Participant-directed services can improve participant satisfaction and early analysis indicates a more effective use of resources in budget terms. More effective use of resources such that the per capita spending is reduced could permit more people to be in the program thereby reducing the size of the waitlist.

The time and effort to implement participant directed services was critical to moving forward with the In-Home Support waiver for families of children with developmental disabilities. Without the DD waiver experience, the State probably would not have moved forward with its newest waiver. The State DD waiver experience is also useful as a model for the State as it implements greater levels of consumer direction in other programs such as the waiver program for the elderly and those with chronic conditions.

Ultimately, New Hampshire's progress and innovation demonstrate what can be accomplished when service users and policymakers can collaborate effectively. Past success in 'thinking outside the box' does not guarantee future success in creative solutions to pressing needs however. New Hampshire staff and advocates indicated that it is always a challenge to think creatively when operating within an existing system, even a highly flexible system like New Hampshire's, but they continue to strive to do so.

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